



Rheumatology Research Center
Center of Excellence
Tehran University of Medical Sciences



MEMORANDUM OF UNDERSTANDING
Systemic Sclerosis Registry Agreement
Rheumatology Research Center, Tehran University of Medical Sciences
and Autoimmune Diseases Research Center, Kashan University of
Medical Sciences

August 2017



Content	Page
<u>Introduction</u>	3
<u>Iran data export</u>	4
<u>Timing</u>	4
<u>Intellectual property</u>	4
<u>Executive Scientific Committee</u>	4
<u>Research projects</u>	
<u>Activities</u>	5
<u>Term and termination</u>	6
<u>Thus agreed upon in duplicate</u>	6



Introduction

Rheumatology Research Centre (RRC), Tehran University of Medical Sciences (TUMS) is mainly based in the Shariati Hospital in Tehran. A registry software is established for different rheumatic diseases, including Systemic Sclerosis or Scleroderma in RRC.

RHEUMA (<http://rheuma.ir/>) is a web software of registry for all rheumatic diseases including Rheumatoid Arthritis, Ankylosing Spondylitis, Systemic Sclerosis, Systemic Lupus Erythematosus, Behcet's Disease, and etc. founded by Rheumatology Research Centre (RRC), Tehran University of Medical Sciences (TUMS). RHEUMA is designed to improve care for rheumatic patients worldwide by monitoring their disease activity. The database can be used as a benchmark by participating rheumatologists and collated data can be a source for scientific research.



Iran data export

RHEUMA is at present interested in Systemic Sclerosis (SSc) components of the Autoimmune Diseases Research Center, Kashan University of Medical Sciences (ADRC) database. RRC will continue to enter all SSc patients in the RRC database, along with all other patients, in a manner that is ongoing.

Timing

Autoimmune Diseases Research Center, Kashan University of Medical Sciences (ADRC) will upload data online.

Intellectual property

ADRC owns its own data and the administrator of ADRC can download and use these data for research purposes at any time. All intellectual and industrial property rights of the data in the RHEUMA database vest in RRC. Therefore it is necessary that ADRC administrator transfer any intellectual property or other rights in the database to RRC. Unless agreed otherwise in writing, the ADRC administrator will not have any license to use the data in the database, other than its own data. All collaborators can use the database in research and publications by permission of RRC and others.

Executive Scientific Committee

RHEUMA Executive Scientific Committee acts as the Board's forum for discussion on strategic and feasibility aspects of RHEUMA. They are a platform for judging scientific questions raised by researchers who wish to utilize the database, while safeguarding the ethical and scientific aspects of RHEUMA. RHEUMA is pleased to welcome Batool Zamani as an Autoimmune Diseases Research Center of Kashan University lead, which will make her a member of the Executive Scientific Committee of RHEUMA, with the possibility to submit research proposals and discuss submitted requests.

Research Projects

Rheumatologists who enter data into the RHEUMA database can submit proposals for research projects, according to a predefined research proposal template. Research proposals are assessed on ethical, scientific and feasibility aspects by the RHEUMA board and the Executive Scientific Committee. Research proposals without a request for funding can be submitted at any time. Research proposals with a request for funding can be submitted once a year. The deadline to submit these proposals, along with the maximum budget and project duration, will be communicated by email.



Activities

Responsible for ADRC export:

Batool Zamani will supervise all operations and be the coordinator.

Responsible for RHEUMA upload:

Toktam Kianifard will supervise all operations and be coordinator.

Mohammad Tanhaei will be functional application manager.

The main objective is to export and upload all SSc components of the ADRC database since August 2017 according to availability and the Import Guidelines Document.

Activity	Responsible
Provide Import Guidelines Document + support	RHEUMA
Test Plan	RHEUMA and ADRC
Test Execution	RHEUMA and ADRC



Term and termination

This agreement enters into force on October 1, 2017 and will expire per August 1, 2020.

RHEUMA's intention is a long term commitment. Terms and conditions of this agreement may be revised yearly.

Thus agreed upon in duplicate

Rheumatology Research Center

Autoimmune Diseases Research Center

Name: Ahmadreza Jamshidi

Name: Batool Zamani

Place: Tehran

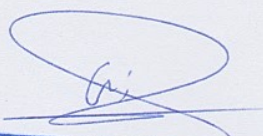
Place: Kashan

Date:

Date:




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